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ABSTRACT

The current standard in providing residential services for individuals with severe disabilities favors serving small groups of people with similar levels of assistance needs in ordinary housing units, which are owned or leased by nonprofit agencies, funded by a mix of federal and state funds, and employ shift workers who provide professionally defined programming targeted on increasing each resident's level of independence. A new standard is developing that emphasizes supporting people to live in their own homes. Two dangers threaten to compromise the new standard. Enthusiasts might dump people with developmental disabilities into squalid or dangerous dwellings in the name of getting people into their own places, or people who want to catch the wave of innovation might resolve the tension between vision and current practice by simply relabeling existing facility types as people's own homes. Steering between these two threats means pursuing an agenda shaped by considering three dimensions of what it means for people to have their own homes. People have their own homes when they experience a sense of place, when they or their agent control their home and the support necessary to live there, and when they occupy the valued role of home owner or tenant and thus build equity or credit through rent or purchase payments. (JDD)

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DOWN STAIRS THAT ARE NEVER YOUR OWN: SUPPORTING PEOPLE WITH DEVELOPMENTAL DISABILITIES IN THEIR OWN HOMES

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Down Stairs That Are Never Your Own

Supporting People with Developmental Disabilities in Their Own Homes

John O'Brien*

> You will come to know how bitter as salt and stone
> is the bread of others, how hard the way that goes
> up and down stairs that are never your own.
>
> – Dante, *Paradise*
> CANTO XVII, 58-60

Most adults with developmental disabilities eat the bread of others and know only the way that goes up and down stairs that are never their own. Either they live in their parent's house or they occupy a bed in a place set up to offer supervision and treatment. Mostly, opportunities to hold one's own lease require the ability to succeed with minimal assistance. Problems usually send a person in difficulty down the steps of the service continuum to a bed in a more restrictive facility.

Until recently this seemed an obvious and necessary consequence of having a severe disability. Today's service systems developed around the unspoken assumption that people could not have both severe disabilities and homes of their own.

The Current Standard

Efforts to develop existing residential services have stimulated vigorous debate. Debates have questioned the optimal size of facilities; the appropriate way to group people in facilities; the desirability of purpose built facilities; the merits of live-in versus shift staffing for facilities; the proper balance of programming and unstructured time in

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facilities; the relative benefits of state or private operation of facilities; and the best mix of funds to overcome the growing shortage of facilities. After twenty years of rapid growth and differentiation in residential service systems, the current standard favors serving smaller groups of people with similar levels of need for assistance in ordinary housing units, which are owned or leased by non-profit agencies, that are funded by a mix of federal and state funds to employ shift workers, who provide professionally defined programming, targeted on increasing each resident's level of independence.

Review of existing residential services reveals substantial limitations in the current standard. There are still far too few places to meet a growing demand. The dollar cost of operating facilities continues to rise. Managers have increasing difficulty recruiting and retaining capable staff. The amount of energy necessary to comply far exceeds the benefits of increasingly complex regulations. Structured programs may increase people's skills, but very few people graduate to independence, and even fewer achieve full community membership. Years of hard work have produced many settings that may be home-like but most really seem much more like small facilities than like people's homes.

A New Standard

A growing number of people actively question the assumption implicit in the current standard. They notice that most debate and development continues to be focused on facilities. They ask why a need for personal assistance should bar people with severe disabilities from enjoying the benefits of life in their own homes. Their struggles and successes define a new standard which emphasizes supporting people to live in their own homes.

The new standard resonates with most people's desire for a home of their own. And the increasing number of stories about positive changes that result when people with severe disabilities have their own places suggests an appealing alternative to the increasingly apparent limitations of facility based services. So, more and more people endorse the mission of supporting people with severe disabilities in their own homes.

Getting to the Roots: A Word History of Home and House

The history of common words illuminates the meanings humans attach to home and house.

The word *home* arises from a Sanskrit root (k'semas) that identifies a safe place to lie down; a separation of outside from inside, defined by a threshold. This sense of safety is elaborated into the social realm through the Gothic (haimo) to mean village and the Old English and Middle English definition of home as a village with its included dwellings. So people are secure at home when they are part of a larger social unit, such as a village or neighborhood.

From about 900 AD, the word home has referred to the center of family economic life, a place where one properly belongs with important other people, and where one finds refuge, rest, or satisfaction. To be away from home is to be out of one's element. To be at home means to be at one's ease and prepared to receive visitors. In some games, home defines the goal and place where a player is safe from attack.

At root, the word *house* is associated with possession, with having, and thus with a family of terms referring back to the Latin domus (such as domicile, domesticate, and domain). Just to have a house means to possess symbolic and legally recognized authority to include or exclude and to have a say. That which is housed is orderly, proper, and familiar. That which is outside housing is undomesticated, strange, and very likely dangerous. (Danto, 1990).

By 1550, English law had created a new task for the word house by naming the workhouse, a place for the enclosure of the poor under the external control of local authorities. Such houses discipline their inmates by sheltering them without offering them the status of guests, the authority of householders, or the security of those who are at home. It is the split of shelter from authority, embodied in the workhouse, that defines the sense and quality of the housing generally available in today's state controlled apartment clusters, group homes, institutions, and nursing homes. Not until the 1850s is the word home appropriated to identify an institution intended to provide refuge for the destitute.

Today, people with severe disabilities and their allies search to restore the older, deeper meanings of home and house and to extend their meaning to people who have historically been, at best, subordinate members of other men's households.

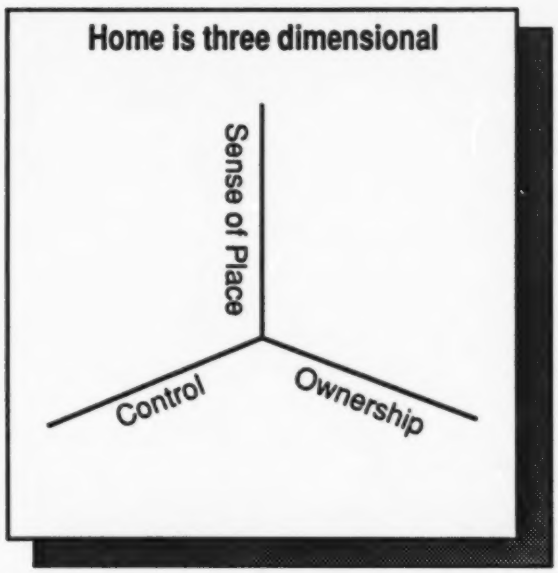
Definitions and derivations are from the *Oxford English Dictionary (2nd ed.)*; E. Partridge (1983). *Origins.* NY:Greenwich and from A. Danto. (1990). Abide/Abode. In L. Taylor, ed. *Housing: Symbol, Structure, Site.* NY:Cooper-Hewitt Museum.

Developing an Agenda for Change

Growing enthusiasm creates a favorable but dangerous climate for change. The vision of people with severe disabilities living with support in their own homes contradicts most current policy and practice. Moreover, work to realize this vision brings significant new problems, risks, and uncertainties. Two immediate dangers threaten to compromise the new standard. Enthusiasts might dump people with developmental disabilities into squalid or dangerous dwellings in the name of getting people into their own places, or people who want to catch the wave of innovation might resolve the tension between vision

and current practice by simply re-labeling existing facility types as people's own homes.

Steering between these two threats means pursuing a demanding agenda, an agenda which can be shaped by considering three dimensions of what it means for people to have their own homes. From this perspective, people with severe disabilities have their own homes when they experience a sense of place, when they or their agent control their home and the support necessary to live there, and when they occupy the valued role of home owner or tenant and thus build equity or credit through rent or purchase payments.



Each dimension of being at home offers people with severe disabilities significant benefits, and each dimension challenges the creativity and political skill of people who want to offer good support. Circumstances in an existing service system and a particular community's housing market offer uneven chances for progress. Work on each dimension is worthy in itself, but people will not arrive in their own homes until they have real opportunities on all three dimensions.

Sense of Place

People with a sense of place comfortably inhabit and personalize their homes. They choose the ways they want to invest their time, skills, energy, and money in the routines of homemaking (like doing the cooking and cleaning), and the many possibilities for home improvement (like making needed repairs or fixing up used furniture), and the work of their household economy (like growing vegetables or making crafts). They have the safety and ease afforded by an adequate physical structure, decent furnishings, and sufficient nourishment. They have the sense of personal security that comes from legally assured tenure, from being recognized as legitimate occupiers by other citizens and by authorities, and from belonging to a neighborhood and perhaps to an extended household that includes supportive family and friends. A sense of place offers people a physical and emotional base from which to depart and to which to return from engagement in outside activities. The threshold captures the essence of a sense of place in that it separates an inside that belongs to and defines dwellers from an outside. Control of the threshold, the power to invite others in or keep them out, gives people who are at home the capacity to offer the gift of hospitality to friends, neighbors, and strangers.

Many current practices deprive people with severe disabilities of a sense of place.

- Many people live in facilities where they only belong because of a service provider's continuing patronage. A service provider is legally and commonly recognized as householder, even if the service provider does not live in the facility. People's continued residence depends on compliance with the service provider's house rules and their compliance with requirements for residence set by professional teams and welfare policies; for example, people may face eviction if they lose their place in a day program. Indeed, if a service provider fails to comply with service system regulations, people with disabilities risk loss of their place to stay.
- People may be moved to another facility if professionals judge that they require more or less intensive programming.
- People may be denied the opportunity to hold a paying job if the system pays for their place in the facility with medical funding which forbids or discourages employment.
- People's schedules, activities, and often their meals and bed times are controlled by professionally approved individual programs.

- Many people need professional approval to join in activities or associations outside the facility. Frequently, people depend completely on the facility they live in for transportation. Often the people who live together must travel together and take part in activities together in order to maintain proper staff-resident ratios.
- People only have as much choice about their use of space, furnishings, possessions, and their own funds as professionals decide to allow. Off limits areas within facilities are common.
- People have very limited control of their threshold. They typically need permission to invite guests. Professionals have the preemptive right to oversee any space and activity; professionally approved room searches are not uncommon.

In typical residential services, including many so called apartment living or semi-independent living programs, people have virtually no personal or social space to call their own and the ways they are required to live enforce their social isolation. Efforts to question or challenge conditions are often defined as symptoms of inappropriate behavior, which justify intensified control. These circumstances reduce people to professionally processed commodities.

Of the three dimensions of being at home, people who provide services have the most power to influence sense of place. However, supporting people to establish a sense of place entangles service providers with powerful assumptions about the appropriateness of professional control of the details of severely disabled people's lives which are embedded in custom and regulations, and with huge investments of funds in large and small facilities, and with welfare policies based on the deeply entrenched belief that reliance on public funds is incompatible with the dignity of being a householder.

Control

People have control of their homes when they have a choice of the place that they live and a choice of the people they live with. The range of choices of place and housemates depends on the amount of money a person has for household expenses and the extent of a person's social network. Someone with more money and more personal contacts has greater control than someone whose budget requires the contribution of several housemates and whose social contacts are limited to a few other people who are also service clients.

Many existing service practices deny people control of their own homes.

- Locations are usually selected by service providers, and many facilities are designed and furnished according to service provider taste and in conformity to safety codes that assume the congregate care of incompetent people.
- The size of households is typically set by policy or by service provider judgments about the numbers necessary for economic viability.
- The people who happen to live together in a facility, and often the people who share a bedroom, are more likely to be selected by the accident of who happens to be eligible for a vacant bed than by mutual agreement among those who live together.

Because people with severe disabilities usually need substantial paid assistance to maintain their household and pursue their personal interests, they can't have effective charge of their daily life unless they have control of the personal assistance they need. As one person who relies on a professionally controlled personal assistance system puts it,

> How long should you wait for an appeal to decide what time you're going to get up in the morning, or how often you can go to the washroom, or whether someone can wait for you for an hour instead of 45 minutes... and, when something changes in your life, how long do you wait to get your attendant care schedule to match what you have to do?... We are just so fettered by the bureaucracies.

People with severe disabilities need the option to control personal assistance funds and manage the people who provide them with help. This means that people with severe disabilities have the choice to hire, fire, schedule, train, and supervise the people who offer them needed everyday assistance.

Some people will choose to completely self-manage their assistance; others will want to delegate some or all of the tasks to an agent, perhaps a user controlled cooperative or a service brokerage agency. Like other citizens, people with severe disabilities will want and use a variety of services, such as physical therapy or cooking lessons, but specialist practitioners will not be in control of people's home life.

Some people's cognitive disabilities are so substantial that they rely on a guardian –usually a family member or friend– to exercise control on their behalf in order to insure that they have a home and a support system that offers them a sense of place and respects their dignity and the individual preferences they do express. A trustee can own a house or hold a lease for a legally incompetent person. A

guardian can monitor a person's home life and make necessary choices in the person's best interest. Though people with profound cognitive disabilities live every minute with the decisions other's make, they can live in their own homes.*

Many people will be capable of making all of their own decisions about the type and amount of assistance they need and about the extent to which they wish to delegate management; some will need assistance or facilitation or guardianship. A service system designed with the presumption that people have complete control over available funds for personal assistance is easy to adjust in order to accommodate people who are unable to manage for themselves. A service system which controls people by requiring professional management of needed assistance is almost impossible to adjust to accommodate people who have the desire and ability to manage this aspect of their own lives.

In the US, federal policy offers substantial incentives to states that choose services that establish professional domination and deprive people of choice. Only a few states organize any of their personal assistance system to allow the option of control by the person who uses services. Typically, apart from small demonstration programs, even very able people with severe physical disabilities must become patients of home heath care agencies or clients of some other professionally controlled agency in order to get the assistance they need. And no state yet invests nearly as much in personal assistance as it pays out for facility based services.

State and federal disability policies most influence the extent to which people with severe disabilities can control their own homes. Policy makers who want to support people with severe disabilities to be at home will challenge and change two crippling assumptions: that inmates of facilities deserve higher levels of per-person expenditure than people who live in their own homes; and, that people who rely on public funds for necessary assistance must be passive and grateful recipients of professional control. In a system that deprives people of adequate funds and choice by policy, service providers can

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* I am grateful to Zana Lutfiyya for reminding me of the importance of explicitly recognizing the needs of people with profound cognitive disabilities for the support of substitute choosers in establishing their own homes.

initiate ways to support choice, but the commitment and skill and luck required will significantly depress the number of people who benefit.

Ownership or Tenancy

People who invest in owning their own home occupy a valued social role. Homeowners have more opportunities to increase their material wealth than tenants with similar incomes. Many people's pride of ownership reflects the fulfillment of a personal dream and frequently motivates efforts to improve and personalize property and strengthen the local social fabric. Many homeowners feel an increased sense of stability and personal security, even if most of their home is owned by a mortgator.

Over the past 20 years, beginning home ownership in the US has become increasingly difficult for all people of modest and moderate means because overall real wage income has failed to rise as fast as the price of homes and the price of mortgage interest. This difficulty has created a variety of experiments. Some responses are private solutions such as significantly increasing the number of hours household members work for wages, developing substantially smaller homes or homes designed for joint occupancy, and implementing a variety of "creative financing" options. A small but growing number of responses arise as people explore associational solutions such as housing cooperatives, community land trusts, and co-housing.

Even these innovations in the housing market leave a growing number of Americans establishing a longer term place of their own in rented quarters. Tenants have the opportunity to establish a strong credit rating and build up their financial and personal resources. Many tenants will continue to work toward their dream of home ownership.

So being, and perhaps remaining, a tenant is an increasingly common social role for Americans. And, given adequate protection for tenant interests, it is easily possible for people to create a sense of place and to maintain adequate control of necessary help in a place one does not own. However, many people with severe disabilities cannot even establish tenancy.

- The typical service practice of tightly linking the funds and the personnel for the necessary assistance to the operation of a facility bars most facility residents from moving into their own places.
- Rising demand for residential service places combines with substantial sunk cost in relatively new facilities, many of which were designed to qualify for federal government cost sharing, to create significant disincentives to providers and service system managers who consider reducing the number of people bound to facilities.
- In most housing markets, a continuing undersupply of physically accessible housing combines with very small amounts of available money for individualized physical adaptations to keep many people trapped in congregate housing.

Even when people with severe disabilities do establish tenancy, the step to ownership is unduly difficult.

- Existing ways of paying for necessary assistance through the welfare system don't allow people to save more than a small amount of money.
- Common practices of spending down or confiscating people's assets to pay for virtually the same services available at public expense discourage families from distributing family resources to a member with a severe disability through gifts or bequests.
- Most residential services have developed in near isolation from local, state, and federal efforts to meet the common need for decent, affordable housing. The typical effect of advocacy for people with severe disabilities has been that some funds are earmarked and used to build congregate facilities. As a result of this cut-off, most people working for better housing consider the housing concerns of people with severe disabilities as properly belonging to some other agency.

Those who want to assist people with severe disabilities to enjoy the benefits of tenancy and ownership will work on three fronts.

- They will separate support services from facilities. Then, people can, if necessary, have the same amounts of assistance under their own roof as would be available to them as an inmate of a facility. This along with specific assistance to negotiate favorable terms with landlords or lenders will encourage individual tenancy.
- They will work with people with disabilities and their families to devise ways to increase the material resources at people's disposal. This effort will combine incentives for saving that make sense to the person with a severe disability, opportunities for paid employment, trust funds, creative real estate development, and vigorous advocacy to change the service system's confiscatory policies.
- They will seek out and join with other concerned citizens to create a variety of public and civic association approaches to insuring a decent standard of affordable housing. They will explore low cost housing development, cooperative own-

ership, community land trusts, and tenant management schemes. As they learn more about these options, they will design necessary adaptations to allow people with severe disabilities to participate.

Testing Practice & Proposals

To put the idea that home is three dimensional to work, use it to evaluate current practice or proposals for improvement. Consider each dimension separately and specifically identify capacities and limitations. Then define ways to safeguard and expand existing capacities and ways to change to overcome limitations. Remember that progress on each dimension calls for substantial change from business as usual in residential service programs and that many desirable improvements will depend on major policy changes or community developments. This table will serve as a reminder of the three dimensions.

Sense of Place	Control	Ownership
• Personalized space & time • Engagement in household activities • Safety & comfort • Security of tenure • Base for outside activity • Means to offer hospitality	• Choice of place to live • Choice of people to live with • Control of necessary assistance	• Individual or cooperative equity or • Tenancy

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A Renewed Relationship

Others can't support a person with a severe disability to establish and enjoy a household without reviewing and renewing the nature of their relationship to people with disabilities. Support only results from a long term relationship that communicates...

...a strong sense that the person with a disability deserves a decent home and the assistance necessary to live there with dignity , and

...a willingness to respect and align with the person's emerging sense of self and developing ability to define and pursue individually meaningful objectives.

Connie Martinez, a leader in Capitol People First of Sacramento, CA, articulates the essence of the kind of relationship that offers people with severe disabilities a genuine alternative to enforced consumption of the bitter bread of others. Those committed to assisting people with disabilities to live in their own homes will find ways to build enduring relationships that embody the quality she captures in this reflection on a critical moment in her own development.

> I always wanted to bake my own bread. But people laughed at me and said, 'It's not possible. You can't read a recipe or measure things. You don't have the skills. Maybe you could watch somebody else make bread or help somebody else make bread, but you can't make your own; not by yourself.' Then I met someone who showed me the ingredients and the measures and the steps and told me, 'You can do it if you really want to.' And I remembered what I was shown. And by myself I made my first loaf of bread. That was the best bread I ever ate because that bread was the bread of my knowledge.